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Making HIV Testing a Routine Part of Medical Care: The State Health Agency Role

Executive Summary

Undiagnosed HIV infection is a major public health threat. According to the Centers for Disease Control and Prevention (CDC), as many as 25 percent of people living with HIV/AIDS (PLWHA) may not be aware that they are infected. These unidentified HIV infections represent a threat to the public's health because the majority of new infections is transmitted by persons who are not aware that they are HIV infected.

In order to reduce the proportion of HIV infected persons who are unaware of their infection, CDC recommends HIV testing as a routine part of medical care in facilities and geographic areas with high HIV prevalence as a key priority in the agency's new initiative, *Advancing HIV Prevention: New strategies for a changing epidemic* (AHP) and in the most recent program announcement to state health agency HIV/AIDS Programs. The purpose of this issue brief is to examine routine HIV testing as one of the strategies available to reduce the rates of undiagnosed HIV infection, focusing on the state health agency's role in related policies and programs.

State health agencies, while not regular providers of primary medical care, have the potential to influence routine HIV testing activities through provider and patient education in order to reduce real and perceived barriers to testing. These barriers can include perceptions among providers that their patients do not need to be tested, that HIV testing is time consuming and laborious, that talking to patients about HIV will be difficult, and that regulations related to testing are confusing and burdensome. Patients' reluctance to seek testing due to concerns over stigma and confidentiality may also be a barrier that complicates the issue.

There are many things that states can do to overcome barriers to routine testing. This paper will discuss six prominent state health agency roles in making HIV testing a routine part of medical care. These include:

1. Becoming familiar with state and federal policies that affect HIV testing.
2. Identifying health care providers in high prevalence settings in order to target the populations they serve for routine testing programs.
3. Building relationships with providers.
4. Reducing provider barriers to testing through education that corrects misperceptions about HIV testing.
5. Reducing patient barriers to testing through educational and anti-stigma campaigns.
6. Partnering with correctional facilities to address the large amounts of undiagnosed HIV infection among incarcerated populations.

Undiagnosed HIV infection is a large problem that puts many Americans unnecessarily at risk for contracting the virus. The state health agency can play a vital role in helping to reduce rates of undiagnosed HIV infection by encouraging the implementation of HIV testing as a routine part of medical care. For many states, much work has already been done to partner with health care providers and the public to help reduce the rates of undiagnosed HIV infection. It is hoped that by employing some or all of the recommendations presented in this issue brief,

states may be able to build upon these existing relationships to help providers incorporate HIV testing into routine medical care.

Introduction

According to the Centers for Disease Control and Prevention (CDC), there are an estimated 850,000-950,000 people living with HIV/AIDS (PLWHAs) in the United States. This includes about 40,000 new infections per year. Furthermore, many persons testing positive for HIV first learn their status less than one year before developing full-blown AIDS,[1] indicating that many PLWHAs do not learn their status until late in the course of infection.[2] In fact, CDC estimates that as many as one in four PLWHAs do not know that they are infected.[2]

Unidentified HIV infections are a threat to the public's health because the majority of new infections is transmitted by persons who are not aware that they are HIV infected.[3] In addition, HIV infected persons who do not know their status are not seeking treatment, putting them at risk for poor health outcomes.[2]

One reason for the large number of persons who do not know their HIV status stems from infrequent or late testing among high-risk populations. In one study conducted from 1994-1999, 43 percent of persons testing positive for HIV developed full-blown AIDS within one year.[2] The CDC-sponsored HIV Testing Survey (HITS I—1995-1996, HITS II—1998-1999) found that common reasons for infrequent or late testing included denial of risk factors, fear of testing positive, and lowered perceived risk possibly from the availability of anti-retroviral therapies.[4]

Evidence suggests that when HIV tests are offered as a routine part of medical care to all patients in a high prevalence area, more HIV infections are identified than when tests are offered based on symptoms or risk behaviors.[5] To increase the proportion of PLWHAs who are aware of their infection, in 1993 CDC recommended that hospitals and clinics in high prevalence areas routinely test all patients age 15-54. However, as of June 2001, few programs have implemented these recommendations.[5]

In order to re-emphasize the focus on routine HIV testing, CDC has identified "making HIV testing a routine part of medical care" as a key priority in the agency's new initiative, *Advancing HIV Prevention: New strategies for a changing epidemic* (AHP) and in the most recent program announcement to state health agency HIV/AIDS Programs. Providers will be encouraged to offer their patients routine, voluntary HIV testing, just as they offer other diagnostic and screening tests routinely.[3] Routine testing efforts will be focused on hospitals and clinics in high HIV prevalence areas, as well as provider groups that see patients who are part of a high-risk population.[6] CDC is also working with the American Hospital Association to offer guidance in the implementation of HIV testing in hospital settings.

The purpose of this issue brief is to examine routine HIV testing as one tool in reducing the rates of undiagnosed HIV infection, focusing on the state health agency's role in related policies and programs. Data for this brief was gathered through a review of available literature and research on routine testing and through interviews with state health agency and federal agency staff. The brief will first assess the effect of some state policies on HIV testing and state health agencies. Second, the brief will look at routine testing programs, exploring the state health agency's role in facilitating their implementation. By examining these aspects of routine HIV testing and its use as a public health tool, this issue brief is intended to provide states with recommendations they may consider to improve their policies and programs.

State and Federal Policies that Affect HIV Testing

Several policies affecting HIV testing may exist in states. These can include confidential and anonymous testing policies, informed consent requirements, pre-test counseling requirements, reporting requirements, and mandatory or routine testing policies for some populations. Many state HIV testing policies are put in place to protect consumers and improve the public's health by ensuring privacy, supplying surveillance data, and allowing test-seekers to understand the implications of their results. When consumers feel that their confidentiality is protected and that they are being given all of the necessary information to enable them to make informed decisions about HIV testing, they may be more likely to seek testing and other HIV prevention services.

For example, 49 states have laws requiring clinicians and laboratories with access to information regarding a person's HIV status to keep this information confidential. All states and the District of Columbia (DC) have policies that require state and local health agencies to keep HIV test results confidential.[7] Also, medical providers are bound by a code of ethics to keep all health-related information private. Because of the profound stigma that is still associated with HIV, however, many AIDS advocates contend that these confidentiality policies may not be sufficient to make people feel secure that if they seek HIV testing, information regarding their HIV status will remain private.

To address issues in HIV prevention, such as stigma, data collection, and patient education, several policies related to HIV testing may exist in states:

Confidential and Anonymous Testing

All states and DC have confidential testing policies. With confidential testing, the patient's name is recorded along with his or her HIV test results, but this information is kept confidential. Only the patient, the clinician or lab administering the test, and the health agency have access to the test results. With anonymous testing, a patient may receive an HIV test without giving any identifying information. The patient is the only person with access to their test results, but the state health agency may receive demographic information regarding persons who test positive.[8] CDC recommends keeping anonymous testing options available to encourage testing among people who want to know their status but do not want to give their names.[7] Forty states and DC offer anonymous testing options.[8]

Pre-test Counseling Requirements

Good counseling before receiving an HIV test can be crucial to a patient's understanding of his or her test result and its impact on his or her health and emotional stability. It can also be critical to prevention efforts.[9] For this reason, many states have policies that require pre-test counseling for all individuals receiving an HIV test. In Maryland, for example, physicians and technicians administering an HIV test to an individual must provide pre-test counseling that includes education regarding HIV infection and methods for preventing transmission, information on the physician's duty to warn,* and assistance in accessing care.[10]

However, CDC recommends simplifying pre-test counseling requirements, when appropriate. Pre-test counseling can be time-consuming and may not be feasible during short medical care visits. In order to ensure that pre-test counseling does not

* **Duty to Warn**: A legal concept indicating that a health care provider, who learns that an HIV infected patient is likely to transmit the virus to another person, is obligated to take steps to warn that person. State laws determine what actually constitutes a "duty to warn." (CDC, 2004)

present a barrier to HIV testing, states may want to consider modifying guidelines for pre-test counseling, so that it is only required when it is most appropriate, such as in response to a patient request.[15] Even when a patient is not offered pre-test counseling, however, they should still give informed, written consent for the test; they should be offered information on the test, the meaning of the results, and where to obtain more information; and patients testing positive should be given post-test counseling to help link them to care and treatment services.

Reporting Requirements

All states and DC now require reporting of HIV infection, in addition to AIDS diagnosis, to the state or local health agency. Thirty-seven states require HIV reporting by name in some or all cases.[8] In some of these states advocates have expressed concern that name-based reporting would discourage HIV testing. Advocates warned that if people knew that their names would be reported to the state health agency upon testing positive for HIV, they may be reluctant to seek testing based on stigma-related concerns. In response to these concerns, CDC funded multiple sites to conduct investigations of the impact of HIV reporting by name on the use of HIV testing in publicly funded counseling and testing programs. Persons at risk for HIV were recruited from various venues and asked about their HIV testing history, knowledge of state HIV reporting laws, and reasons for delaying or not seeking HIV testing. This CDC-sponsored HIV Testing Survey (HITS) was conducted in several phases. The first HITS survey was conducted in nine states from 1995 – 1996,[25] while HITS II was conducted initially in 7 states from 1998 – 2000.[26] Data from these studies showed that knowledge of state HIV reporting policies was low, and did not significantly impact decisions to be tested for HIV.[11,27,28,29,30,31,32]

However, due to some of these concerns, several states have opted to report HIV infections using other methods. Specifically, nine states and DC report HIV positive test results using codes, and five states use a name-to-code system.[8] In a code-based system, a unique identifier is assigned to each person receiving an HIV test. The identifier is a code made up of various personal numbers such as part of the social security number, part of the birth date, numerals assigned by gender or race, and others. In a name-to-code system, the HIV positive result is first reported to the health agency with the person's name, but the name is later replaced with a code in the agency's database.

Mandatory or Routine Testing Policies

The federal government requires HIV testing for several groups of people, including federal prison inmates, military applicants and active duty personnel, foreign service personnel, blood donors, and immigrants.

Travelers to the United States entering the country on educational visas or for religious purposes are not required to be tested, and waivers may be granted for HIV infected immigrants.[7,8] Some states have mandatory testing policies for certain people as well. Two states, New York and Connecticut, have laws requiring HIV testing for newborns when the mother's HIV status is unknown.[12] In addition, 19 states have laws making HIV testing mandatory for all inmates entering prisons and jails, and three states test all inmates upon release.[13]

Laboratory Licensing Requirements

The Centers for Medicare and Medicaid Services (CMS) regulates all medical testing through the Clinical Laboratory Improvement Amendments (CLIA). Any facility that performs HIV testing, such as health care facilities or community-based organizations (CBOs), must be licensed as a laboratory under CLIA and receive a registration certificate. Various types of registration certificates are issued based on the

complexity of medical testing that the facility is eligible to administer.[14]
Processes for applying for CLIA registration certificates can be confusing and difficult. In addition, some HIV testing technologies, such as the new HIV rapid tests, are considered moderately complex under CLIA, and many CBOs that provide HIV testing services may not be eligible to administer them.[14,17] State health agencies can work with CBOs and health care facilities in their states to help them apply and qualify for CLIA certificates.

The State Health Agency Role in Routine Testing

Identifying Health Care Providers in High Prevalence Settings

State health agencies work with their state and local HIV prevention community planning groups (CPGs) to identify populations at high risk for HIV, and areas within the state with high HIV prevalence rates.[17] As CDC recommends targeting high-risk populations and high-prevalence communities for routine testing programs, the CPG can identify high risk settings where health care facilities and providers can be targeted to promote HIV testing as a routine part of medical care. CDC offers several criteria that can be used to determine if a health care facility or provider should be targeted, including an HIV prevalence rate of more than 1 percent among patients, an AIDS diagnosis rate of 1 per 1,000 or higher among patients discharged from the health care facility, receipt of funds from grantees of Title I or II of the Ryan White CARE Act, or data demonstrating that the patient population has similar characteristics to populations at high risk for HIV in the state.[15]

According to the Wisconsin Division of Public Health, identifying priority populations and communities is the primary role of CPGs. The planning groups use epidemiological data provided by the state health agency to identify those groups of people and areas of the state with the highest incidence and prevalence of HIV infection, and make recommendations to focus resources and programs there. In Wisconsin, the CPG has identified racial minority groups and men who have sex with men (MSM) of color as emerging communities of need. Therefore, the state health agency focuses their routine testing efforts on providers and health care centers in areas indigenous to those populations.[18]

Building Relationships with Providers

As previously stated, one of the goals that CDC outlined in the most recent program announcement to state health agency HIV/AIDS programs is to increase the proportion of HIV infected persons who know they are infected through HIV testing activities. One of the activities CDC proposes to meet that goal is "increasing the number of providers who routinely provide HIV screening[†] in health care settings."

Accomplishing this goal requires significant action on the part of primary care providers. Therefore, the fundamental role of state health agencies in this effort is to build relationships with providers. Research shows that many primary care providers do not perceive a need for HIV testing among their patient population, and are therefore less likely to offer the test to patients as a part of regular medical care. Strong collaborative relationships with State Primary Care Associations, primary care physicians, and other health care professionals who provide regular medical care may allow state health agencies to encourage routine testing through educating

[†] Screening is performing a test for all persons in a defined population regardless of clinical symptoms or behavioral risk factors. CDC recommends HIV testing as part of routine medical care in facilities with high HIV prevalence among patients.

providers on the need for HIV testing and "contract management." Contract management may include technical assistance, monitoring and oversight of providers' HIV testing activities, licensing, and funding activities.

For example, the New York State Department of Health has a long standing history of collaboration with the state's community health centers, ambulatory clinics, and substance abuse treatment providers. For many years, the health agency has consulted with providers on public health initiatives and has made a concerted effort to incorporate their input into policy and program decisions. The health agency gathers provider input through focus groups and surveys. Because of this collaborative relationship, the state health agency often gets high levels of provider participation in its educational activities.[16]

In addition, the New York State Department of Health engages in "contract management" with private providers, including quality oversight of HIV testing activities. To accomplish quality oversight goals, the Department of Health makes field visits to testing sites to provide direct technical assistance, interviews with staff, and medical chart reviews. The Department of Health also develops client satisfaction surveys and distributes them to providers, who then administer the surveys to their patients. The anonymous completed surveys are sent to the Department of Health, who compiles and analyzes the results. A summary of the data is then shared with the providers.

The Pennsylvania Department of Health engages in similar "contract management" activities with providers involved in HIV testing. For instance, field staff from the Pennsylvania Department of Health, Division of HIV/AIDS, provide technical assistance and education to providers on populations at risk for HIV, talking to patients about risk behaviors, and the importance of HIV testing. The state health agency field staff concentrates their educational outreach efforts on primary care providers in high HIV prevalence areas, physicians who provide care to HIV infected patients, and providers working in sexually transmitted disease (STD) and tuberculosis (TB) clinics.[17]

The Pennsylvania Department of Health has a very strong relationship with public health providers.[‡] They maintain that relationship through sharing public health news, clinical and policy information, and providing opportunities for networking among health professionals. In addition, the Pennsylvania Department of Health partners with the Pennsylvania Medical Society and other provider membership organizations to share crucial public health information with private providers. For instance, when studies indicated that the drug Zidovudine could reduce the risk of mother to child HIV transmission when taken by HIV infected pregnant women, the state health agency partnered with the American College of Obstetricians and Gynecologists (ACOG) to share this information with providers. Partnering with ACOG allowed the Pennsylvania Department of Health to encourage obstetricians and gynecologists to offer routine HIV testing to all pregnant women so that those testing positive could seek antiretroviral therapy and reduce the risk of transmitting the virus to their unborn children.[17]

Eliminating or Reducing Provider Barriers to Testing

A second vital role of the state health agency in increasing the number of providers who routinely provide HIV screening in health care settings is to eliminate or reduce perceived barriers to testing for providers. These barriers can include perceptions

[‡] Public health providers offer health care services as part of the state's public health system. These can include public health clinics, health care professionals who provide services within these clinics, or the state health agency.

among providers that their patients do not need to be tested, that HIV testing is time consuming and laborious, that talking to patients about HIV will be difficult,[16] and that regulations related to testing are confusing and burdensome. Also, there may be a lack of awareness of HIV care resources available to patients who test positive.[18]

If strong collaborative relationships exist between the state health agency and primary care providers, many of these barriers can be reduced or eliminated through education, public program announcements, and media campaigns. For instance, according to the Wisconsin Division of Public Health, providing training opportunities, conferences, and workshops for health care providers on testing methods, testing technologies, and giving positive test results may help ease some providers' reluctance to test.[18] In addition, HIV/AIDS service providers can be utilized as resources for training opportunities. CBOs that regularly work with HIV infected persons, or persons at risk for HIV infection, have expertise in HIV testing, at-risk populations, talking to patients about risk factors, and giving positive test results. These CBOs can be called upon to share their expertise and train primary care providers.[16]

Also, it is important to use surveillance data to help providers understand the need for HIV testing in their communities.[18] Along with the surveillance data, state health agencies may consider supplying information to providers on the frequency of test-seeking among certain at-risk populations and estimates of the rates of undiagnosed HIV infection in their communities. Providers can be made aware that many populations are at risk for contracting HIV, but may not be aware of their HIV status. This leads to high rates of undiagnosed HIV infection, which puts many people at risk for transmitting the virus unknowingly.

In addition, it is important to ensure that providers understand confidentiality requirements, informed consent policies, and HIV and AIDS reporting requirements. When these policies are unclear, this may lead to the perception among providers that state regulation of HIV testing is confusing, and following these regulations would be burdensome and time-consuming.[18,16]

Another way that state health agencies can help reduce barriers perceived by providers is to help ensure that there is a good HIV/AIDS care and treatment network in place. Some providers may face an ethical challenge in identifying newly diagnosed HIV infected persons when they do not have care resources available for those patients.[19] It is important not only that care and treatment resources are available to PLWHA, but also that providers are familiar with these resources and can refer patients newly diagnosed with HIV to appropriate care.[18]

Many state health agencies provide some HIV care and treatment through the Ryan White CARE Act. However, the most prominent role of the state health agency in linking newly diagnosed HIV infected persons to care is facilitating a network of care services that connects primary care providers with HIV care providers.[18] States may want to work with State Primary Care Associations, AIDS Education and Training Centers and state medical organizations to develop a database or other resource that includes a listing of all HIV/AIDS service providers in the state, and provides information on types of services offered and patient eligibility requirements. This resource should be accessible to all primary care providers. Public health field staff could inform providers of this resource during regular provider outreach.

Finally, some providers may be experiencing financial or human resource barriers to routine HIV testing for their patients. For instance, funds to purchase tests, reimbursement from insurance carriers for counseling and testing services, and understaffing may all present obstacles to

routinely testing all patients in a provider's practice.[16,19] State health agencies may want to consider using a portion of their HIV prevention budgets for in-kind assistance to primary care providers to help alleviate these barriers. In Pennsylvania, for example, the Department of Health supports providers in their efforts to make HIV testing routine by supplying field staff to conduct HIV testing, viral load and CD4 testing, and partner counseling and referral services (PCRS), upon request.[17]

Overall, it is important that state health agencies have frequent communication with the primary care providers in their states and listen to the obstacles that they are facing in implementing routine testing. State health agencies may assist providers with overcoming these barriers when possible, but also realize that some barriers may be difficult to conquer.[16]

Eliminating or Reducing Patient Barriers to Testing

Although public perceptions of HIV infection in the United States have evolved substantially since the early days of AIDS, there still exists a profound stigma surrounding the disease and those living with it. Many people do not seek HIV testing for fear that a positive test result could cause their families, sex partners, and communities to perceive them negatively. In addition, people may not get tested because they fear that they will be discriminated against, in employment or housing, based on their HIV status, or they may not believe that they are at risk for HIV. The state health agency can play a vital role in helping to eliminate or reduce these barriers and encourage people in their states to get tested.

One role of the state health agency in this arena is to continue to work to reduce stigma. This can be done through outreach activities, media campaigns, and National HIV Testing Day activities. For the latter, the Pennsylvania Department of Health has found that public testing of a prominent group of well-respected community members can help normalize HIV testing for the public. In June of 2003, a group of ministers was publicly tested on National HIV Testing Day. The ministers encouraged other Pennsylvanians to get tested, spreading the message that anyone may be at risk for HIV.[17] In Louisiana, HIV prevention CPGs organize National HIV Testing Day activities in their regions. Some of Louisiana's testing sites offer incentives, such as meals or tickets to events, to people who participate in testing day.[19]

Media campaigns can be useful in reducing stigma-related barriers to HIV testing. Many states have used such media tools as radio and television ads, posters, and billboards to send the message that knowing one's HIV status is essential to maintaining good health.[17] Also, the Kaiser Family Foundation, a national health information and research organization, and Viacom, a worldwide media company, have partnered together to develop Know HIV/AIDS, a national media campaign designed to reduce stigma and encourage testing. This campaign uses radio, television, outdoor, and print media to disseminate information on risk behaviors, reducing risk, HIV/AIDS incidence data, and HIV testing. The campaign's website and hotline also refer people to HIV testing sites in their areas.[20]

The state health agency can also be instrumental in educating people on state and federal policies that protect their confidentiality and prohibit discrimination based on HIV status. As previously stated, 49 states have confidentiality laws that specifically protect HIV-related health information.[21] Aside from confidentiality laws, all medical providers are responsible for keeping health-related information private. In addition, people living with HIV/AIDS are protected from discrimination in employment, housing, transportation, and public accommodations by the Americans with Disabilities Act (ADA). The ADA also prohibits employers from inquiring about an applicant's health or

requiring an HIV test prior to an offer of employment. The employer may require a physical examination after the offer of employment has been made. However, the employer may not decide not to hire a person based on his or her HIV status.[22]

Partnering with Correctional Facilities

Incarcerated populations are disproportionately affected by HIV and AIDS.[23] In 1999, 2.3 percent of state prison inmates, 0.9 percent of federal prison inmates, and 1.7% of local jail inmates were known to be HIV infected.[24] In addition, high rates of infection among incarcerated populations present a risk to communities, as persons detained in correctional facilities are often released after short stays. Therefore, programs that provide HIV prevention services in prisons and jails are important to help protect the public's health.[23]

Many states are utilizing the opportunity to partner with correctional facilities by implementing routine testing programs in prisons and jails. For example, the Louisiana Office of Public Health has implemented demonstration projects for HIV rapid testing in correctional settings. Correctional settings that have rapid testing demonstration projects include prisons, jails, release programs, probation and parole, and court-ordered drug treatment facilities. One challenge to routine testing of inmates in correctional facilities in Louisiana involves the link between testing and HIV or AIDS treatment and care. As in all states, if an inmate is known to be HIV infected, the state is required to provide treatment. With state budgets already stretched thin, some correctional facilities may be reluctant to provide HIV testing because they cannot afford to treat inmates who test positive. However, the Louisiana Office of Public Health anticipates that the demonstration projects may help open the door to corrections-based testing programs and reduce the rates of undiagnosed HIV infection in the state.[19]

Conclusion

Undiagnosed HIV infection is a large problem that puts many Americans unnecessarily at risk for contracting the virus. The state health agency is in a unique position to help reduce rates of undiagnosed HIV infection by encouraging the implementation of routine HIV testing programs.

Some steps that state health agencies may want to consider taking to help make HIV testing a routine part of medical care include:

- Becoming familiar with state and federal HIV testing policies, and assessing how these policies affect HIV testing in their states;
- Working with HIV prevention community planning groups to identify populations at high risk for HIV, and areas within the state with high HIV prevalence rates;
- Building collaborative relationships with public health and private primary care providers;
- Educating providers on the importance of making HIV testing part of routine medical care;
- Reducing providers' real and perceived barriers to testing, including concerns that HIV testing is time-consuming, discussing test results or risk behaviors will be uncomfortable, and HIV testing regulations are confusing;
- Reducing patient barriers to testing including fears of stigma and discrimination; and
- Partnering with correctional facilities to implement routine testing programs in those settings.

State health agencies have a difficult but vital role in making HIV testing a routine part of medical care. For many states, much work has already been done to partner with health care providers, correctional facilities, and the public to help reduce the rates of undiagnosed HIV infection. It is hoped that

by employing some or all of the recommendations presented in this issue brief, states can build upon these existing relationships to implement or improve routine HIV testing programs.

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